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Editorial

An inclusive society?

Peter McGill, Tizard Centre

Winterbourne View

Most readers will be aware of the BBC Panorama programme on the events at Winterbourne View. TLDR does, however, have a number of overseas readers who may not be aware of the programme so a brief introduction is required. The programme, shown on British television on 31 May, was made with the assistance of a hidden camera. It showed the verbal and physical abuse of a number of people with learning disabilities in a private hospital near Bristol. While the provision was private, the costs were borne by the public purse with most of the people there being funded by the NHS at rates averaging £180,000 per year.

The programme has provided a further reminder of how easy it is for things to go wrong in supporting people with learning disabilities. Of course, first thought should go to the individuals involved and their families. In previous such incidents, well-intended but knee jerk responses have led to the wholesale removal of individuals to other settings. Not only has this usually happened without adequate consultation with individuals and their families, it has often resulted in a continuing failure to find a stable and supportive environment. Winterbourne has now closed and it appears that the majority of its residents have been moved to other hospital settings. Let us hope that the authorities responsible for the ongoing care of the individuals involved remember that these individuals are the primary victims and everything that can be done should be done to ensure that the damage done to them over who knows how many months or years is put right as far as it can be. In particular, more must be done to provide the support necessary for them to live in good quality, local community services.

Such considerations also apply to the individuals' families. Put yourself in their position for a moment. Your son or daughter has significant disabilities and both professionals and family members have doubtless struggled to respond adequately to the behaviours they present or the distress they experience. At some point, perhaps after several other placements, your son or daughter is sent, at considerable cost to the public purse, to an "assessment and treatment" unit run by a large, national provider with apparently considerable specialist expert resources. Maybe now your son/daughter will get the help that they need. But over the months you begin to wonder...not much seems to be happening...what treatment are they getting?...is this really doing any good? Maybe too you pick up that there may be problems – your son or daughter doesn't seem to like some of the staff or complains about this or that or has an unexplained bruise or stops liking showers. But this is a specialised unit arranged by your local NHS, surely everything is ok? Then you discover that everything is not ok. The first person you blame is yourself, for allowing your son/daughter to go through this, for not working out what was going on...for failing in your duty to protect your child. You are not to blame! Your son or daughter is not to blame! The families of the individuals living at Winterbourne now need considerable support themselves. The first step in this is to make sure that nothing is hidden, that there are no surprises years down the line during the inevitable investigations. They need to know the worst now and be given the help needed to deal

with it. They need support from each other and from other families who understand what they're going through.

Inevitably, the programme will lead to discussion of why such things happen and how they can be prevented. There are no easy answers here but I would like to draw attention to three things that could make a difference.

First, we mustn't treat the events shown in the programme as simply being the result of bad people doing bad things. There have been too many such events over the years to allow this interpretation. We all know that similar things happen elsewhere. If we allow the programme to be portrayed as exceptional we risk missing one of the main lessons. That is that the kind of treatment seen on the programme reflects the broader social status of people with learning disabilities. This is not a status to which anyone would aspire. It is one in which, in our society it seems to still be "acceptable" to discriminate against people with learning disabilities in health, employment, education, leisure and a range of other areas. Worse, it is one likely to be associated with bullying and hate crime. The society in which people walking down the street can be derided loudly as "raspberry ripples" by others is the same society in which people can be abused, punished and treated as less than human at Winterbourne View. Events such as those shown in the programme happen in the community too, with sometimes appalling results such as the murder of people with learning disabilities and the suicide of carers and their sons/daughters (see, for example, <http://www.guardian.co.uk/society/2011/jun/01/disability-hate-crime-keith-philpott>). They will only cease when we become better able as a society to accept and include people who are "different". This is a hard ask but is no more than the kind of change in British society over the last 40 years in respect of people from black and ethnic minorities. We need to learn from that and other similar broad social changes how to make things different.

Second, and another reason for not taking the easy route and simply demonising the staff involved in the incidents, it was very clear on the programme that staff simply did not know what to do. If you don't know what to do, and no one is telling you what to do, you make it up as you go along. You are influenced by those around you, especially those with the loudest voices. Very soon, a culture develops in which the very things that will later be regarded as abusive and even criminal are simply elements of your culture, the way in which you, unthinkingly, practice your trade. Staff in these situations have also been let down. No one has told them what to do, no one has shown them what to do, no one has pointed out the error of what they are doing. The job they are doing is difficult and skilled. If you don't know what to do, it is unlikely that you will invent the best ways of doing it by yourself. Instead, we need to give much more attention to developing the skills of the staff who work in these kinds of settings. This is not just about NVQs or the like, it's about serious training and supervision so that all staff understand why the people they are working with behave as they do and both know and believe in the best ways of working with them. It is absolutely astonishing that we are still in this situation, where we spend a fortune on services for individuals that are no more than glorified babysitting. I realise this is not an entirely popular view. One of the least appetising aspects of the reaction to the programme was the vigilantism directed at the staff involved with, for example, staff addresses being published on Facebook and calls to "go to their houses Friday night". While this was an extreme response of a small minority, many people would still find it difficult to avoid seeing the staff involved as being entirely unsuitable for the kind of work they were employed to do. I am not in the business of defending these staff, simply noting that they are not that different

from the rest of us and that to see their behaviour as entirely stemming from their “evil” will not help us prevent future such incidents.

Third, Winterbourne is in some respects no different to all the other places in which such abusive practices have been “uncovered” – it is, in a very real sense, “covered” i.e. hidden from plain sight so that as a culture in which unacceptable practices become acceptable there is no one to question what is happening, no one to say “hang on a minute, that can’t be right”. This is the traditional closed institution where anything can be got away with. It was even, astonishingly, the case that when family members visited they had to see their relative in a “visitor’s room”. The antidote has to be openness, transparency. There is, of course, a potential conflict here between the privacy of individuals and such transparency. But we must build on approaches like advocacy to ensure that it is very hard to get away with the kinds of practices found at Winterbourne without detection. The advocate role is one of the least developed in provision for people with learning disabilities yet one with great potential.

There will, no doubt, be extensive enquiry into the events at Winterbourne. This is as it should be. In the rush to blame, however, the staff, the provider, the regulator, the commissioners and so on we must not forget the reasons why such events happen in the first place. Only by attending to the root causes of the problem can we hope to prevent similar events now and in the future.

The current issue

Coincidentally, the articles in the current issue all relate to discrimination in some way. Claudio Pestana provides some rich, qualitative information on the lives of four people with learning disabilities from ethnic minorities. Their experiences sadly include both a failure of support in respect of their cultural needs and being abused both by virtue of their learning disability and their cultural background. Raghu Raghavan, in his commentary, points to the increasing importance of health and social care professionals becoming more culturally competent if they are to ensure their services are accessible and helpful to all parts of the community. The motivation for the development of the Confidential Inquiry into the deaths of people with learning disabilities was, as Beverley Dawkins points out, the evidence of “institutional discrimination” in healthcare. Pauline Heslop and Anna Marriott outline the progress made with the Inquiry to date and the ways in which it is intended to reduce discrimination and improve health outcomes. Alan Leyin, focusing on the Improving Access to Psychological Therapies programme, asks if enough is being done to ensure that people with learning disabilities have adequate access to the kinds of treatments for anxiety and depression now being made available on a more widespread basis.

In the end, of course, it is no real coincidence to find it easy to identify discrimination as a theme in this issue (or most others). This reflects its prevalence in the daily lives of people with learning disabilities and their families. Part of my argument, in reviewing the Winterbourne events, is that the occurrence of abuse such as this is part of a bigger picture which is exemplified by the articles in this issue. A society which routinely discriminates against people with learning disabilities is much more likely to produce a Winterbourne View than one which is routinely inclusive and positive about diversity. How do we create an inclusive society? This would, perhaps, be an interesting question to address in a special issue of TLDR. Clearly, it requires attention to the attitudes and behaviours of all

members of society, not just those most directly involved in supporting people with a learning disability. In all likelihood, it requires new approaches in education, employment, leisure and domestic life. It would be hard, in such a society, to see a place for a Winterbourne View or any of the other hospital or “specialist” settings in which so many people with learning disabilities still live.